

Seton Hall University eRepository @ Seton Hall

Law School Student Scholarship

Seton Hall Law

5-1-2014

Savior Siblings: The Ethical Debate

Kristie Lauren Trifolis

Follow this and additional works at: https://scholarship.shu.edu/student_scholarship

Recommended Citation

Trifolis, Kristie Lauren, "Savior Siblings: The Ethical Debate" (2014). *Law School Student Scholarship*. 432.
https://scholarship.shu.edu/student_scholarship/432

Savior Siblings: The Ethical Debate

Kristie Trifolis

I. Introduction

Molly Nash was born into the loving arms of parents Lisa and Jack Nash in 1994. When she was six years old, it was evident that something was wrong with Molly's immune system.¹ Her parents received the shocking news that Molly was suffering from Fanconi anemia, a deadly genetic disorder characterized by failure of bone marrow production.² Lisa and Jack's only option to save their beloved six year old daughter was to conceive another child who would act as a donor to his or her big sister.³

Adam was born on August 29, 2000.⁴ A team of doctors performed a stem cell transplantation as soon as he was born and infused these cells into Molly's circulatory system.⁵ After four weeks, Molly showed bone marrow recovery and three years later her immune systems were normal.⁶ Adam is a savior sibling conceived in vitro to increase the chances of survival or quality of life of his sister.⁷

What this paper will do is describe in detail the process by which this is procedure is performed by discussing the important roles of in vitro fertilization and Preimplantation Genetic Diagnosis. The next section of this paper will focus on the ethical considerations surrounding the

¹ Amy T. Y. Lai, *To Be or Not To Be My Sister's Keeper?*, 32 J. LEGAL MED. 261, 261 (2011).

² *Id.* at 262.

³ *Id.*

⁴ *Id.*

⁵ *Id.*

⁶ *Id.*

⁷ Tim Harrison, *Are Savior Siblings a Humane and Proper Use of Reproductive Technology?*, 2008, available at <http://www.nimr.mrc.ac.uk/mill-hill-essays/are-saviour-siblings-a-humane-and-proper-use-of-reproductive-technology>. (last visited April 24, 2013).

idea of the creation of a savior sibling. That section will start off by discussing how this idea has been mainstreamed through media, followed by the three main arguments against this process: (1) children as commodities; (2) the creation of “designer babies”; and (3) the welfare of the child. The last part of the ethical section goes through tests that are sometimes used to explore the ethical idea of a savior sibling. The following section targets the four different types of structures of law that are most commonly used by the United States and many other countries in an attempt to regulate the use of Preimplantation Genetic Diagnosis. Following the discussion of laws, several U.S. cases will be analyzed that, although not directly on point, help illustrate certain points and considerations. The last section of this paper will consist of opinions and conclusions based on the following research.

II. The Process of Creating a Savior Sibling

The term savior sibling usually refers to a baby that is created using in vitro fertilization (IVF) that was screened during the process using Preimplantation Genetic Diagnosis (PGD) to act as a donor match for a child who already exists and is sick in some way.⁸ It is important to understand the process of creating a savior sibling before an analysis of the ethical considerations can be made.

In vitro fertilization is fertilization of an egg that happens outside of the body.⁹ A woman takes fertility drugs to produce several eggs which are then fertilized by male sperm by being

⁸ N. R. Ram, *Britain's New Preimplantation Tissue Typing Policy: An Ethical Defence*, 32 J. MED. ETHICS 278-282, 278 (2006).

⁹ *Id.*

mixed together in a petri dish and then harvested by a doctor.¹⁰ Fifteen eggs is the recommended number to harvest.¹¹ The embryos are then grown for somewhere between two to five days.¹² At that point, the ‘best’ embryos are chosen, based on number of cells, evenness of growth, and various other factors, and then implanted into the woman’s uterus.¹³ IVF has been occurring since 1978 and the success rate in 2011 was about one child birth in three attempts.¹⁴ Studies have shown that, although sometimes with multiple attempts, two thirds of couples who try IVF eventually have a baby.¹⁵

Pre-implantation genetic diagnosis (PGD) is the process of screening IVF embryos to prevent inherited disorders.¹⁶ The PGD procedure usually occurs at about day three.¹⁷ At this point the embryo is around six to ten cells in size.¹⁸ Acid is used to get inside the embryo, and a thin pipette sucks out one cell from the embryo.¹⁹ This is done by holding the embryo securely and having a carefully controlled stream of acid blown through a thin pipette in order to drill a hole in the shell of the embryo.²⁰ The cell taken is then screened to identify whether the fetus

¹⁰ Fertility Factor, *Getting Pregnant: In Vitro Fertilization*, 2013, available at

http://www.fertilityfactor.com/infertility_in_vitro_fertilization.html, (last visited April 24, 2013).

¹¹ Jenny Hope, *Why 15 Harvested Eggs is the Magic Number for an IVF Birth*, (2011), available at <http://www.dailymail.co.uk/health/article-1385709/IVF-15-harvested-eggs-magic-number-successful-live-birth.html>, (last visited April 24, 2013).

¹² Fertility Authority, *It Takes Two*, 2013, available at <http://www.fertilityauthority.com/articles/it-takes-two>, (last visited April 24, 2013).

¹³ BioTech, *In Vitro Fertilization Procedure: Applications, Advantages, and Disadvantages*, (2012), available at <http://www.biotecharticles.com/Applications-Article/In-Vitro-Fertilization-Procedure-Applications-Advantages-and-Disadvantages-567.html>, (last visited April 24, 2013).

¹⁴ RsRevision, *Saviour Siblings*, 2011, available at http://www.rsrevision.com/GCSE/christian_perspectives/genetics/saviour_siblings/introduction.htm (last visited April 24, 2013).

¹⁵ *Id.*

¹⁶ Penn Medicine, *Preimplantation Genetic Diagnosis*, 2013, available at <http://www.pennmedicine.org/fertility/patient/clinical-services/pgd-preimplantation-genetic-diagnosis/> (last visited April 24, 2013).

¹⁷ See RsRevision, *supra* note 14.

¹⁸ *Id.*

¹⁹ *Id.*

²⁰ Shiraz Fertility Center, *Embryo Transfer and Embryo Implantation*, 2009, available at <http://www.shirazinfertilitycenter.com/en/EmbryoTransfer>, (last visited April 24, 2013).

might develop a genetic disorder.²¹ PGD can also be used to check if a new baby would be a donor match for an existing sick child.²²

When the embryo is selected and eventually born, blood from the umbilical cord is usually used to treat the sick sibling.²³ If this does not work, a bone marrow transplant or some other tissue or organ transplant may be necessary at some later stage.²⁴

The physician who is along for ride during this process is an important stakeholder for several reasons.²⁵ First, he or she is the one who starts the entire process of explaining and initiating the concept of a savior sibling to the parents.²⁶ The physician, in a sense, serves as a beacon of hope for these parents trying to save their child.²⁷ It is important to remember that the physician is doing his or her job by discussing the options to save a child, and, therefore, might not realize “the unethical chain of events that can result from a mere suggestion.”²⁸

The Hippocratic Oath, which physicians tend to recite, states, “I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person’s family and economic stability.”²⁹ In an article by Mariana Do Carmo, she explains that the phrase “not a cancerous growth, but a sick human being” can be a very powerful phrase in justifying the physician’s decision to bring up the idea of a savior sibling to save another child at all costs.³⁰ This doctor will also most likely serve as the savior child’s physician as well.³¹ The

²¹ Genetics Home Reference, *Genetic Testing*, 2013, available at <http://ghr.nlm.nih.gov/handbook/testing?show=all>, (last visited April 24, 2013).

²² Katy Duke, *Belgian Loophole Allows Swiss Parents a Savior Baby*, 368 THE LANCET 355 (2006).

²³ See RsRevision, *supra* note 14.

²⁴ *Id.*

²⁵ Mariana Do Carmo, *Child Autonomy and the Rights to One’s Own Body: PGD and Parental Decision Making*, 2013, available at <http://www.thebioethicsproject.org/essays/child-autonomy-and-the-rights-to-ones-own-body-pgd-and-parental-decision-making/>, (last visited May 9, 2013).

²⁶ *Id.*

²⁷ *Id.*

²⁸ *Id.*

²⁹ *Id.*

³⁰ *Id.*

³¹ *Id.*

acts of the physician are not done out of a want to hurt another child, but as a means to save an existing child.³² While the physician cannot make the choice for the parents, they must explain the consequences to the parents of creating a child using PGD.³³ A physician can, however, step in and advocate for the rights of a savior child if that physician feels as though the child is being mistreated.³⁴

III. The Ethical Considerations

A. Savior Siblings Go Mainstream

The idea of savior sibling went mainstream when a famous novel, later converted into a movie, entitled *My Sister's Keeper*, allowed the idea of a savior sibling to become a well-known topic to the world. This novel is based on a family faced with the idea of creating a savior sibling to keep another sibling alive. In 1990, Kate was diagnosed with a rare and aggressive form of leukemia.³⁵ Kate began chemotherapy almost immediately, and her oncologist suggested she might eventually need a bone marrow transplant from a related donor.³⁶ The family tested their four-year-old son but he was not a match.³⁷ The doctor suggested that another unborn sibling could be a match and that maybe the family should consider having another child in an attempt to save Kate.³⁸

³² *Id.*

³³ *Id.*

³⁴ *Id.*

³⁵ JODI PICOULT, *MY SISTER'S KEEPER*, (2003).

³⁶ *Id.*

³⁷ *Id.*

³⁸ *Id.*

The novel is told from the eyes of Sara, the mother, who focuses on the struggles that Kate endures.³⁹ Anna, the savior sibling, is a perfect genetic match for Kate and over the course of a few years, Anna undergoes several procedures including frequent blood withdrawals and painful bone marrow extractions in an effort to keep her sister alive.⁴⁰ Sara and her husbands' relationship starts to spin out of control because Sara's sole focus is on Kate.⁴¹

The most interesting part of the novel is when Anna, now thirteen, goes to see a lawyer and asks him to represent her.⁴² Anna wants to sue her parents for medical emancipation.⁴³ She did not want to donate a kidney to Kate, who is in the end state of a kidney failure.⁴⁴ When Sara was served with the papers for the lawsuit she was enraged at Anna.⁴⁵ The judge in the case appointed Anna a guardian ad litem whose sole job was to objectively decide what was in Anna's best interests.⁴⁶ Anna takes the stand at trial and admits that she filed the lawsuit only because Kate asked her to.⁴⁷ *My Sister's Keeper* is an emotionally jarring novel that truly speaks to the idea of a savior sibling and what impacts it has, as well as touching largely on one of the three main arguments that will be discussed below.

B. Arguments

The three main arguments that can be found when it comes to the idea of creating a savior sibling are that savior siblings would be treated as commodities; the second is a slippery slope argument basically suggesting that this type of practice will eventually lead to the creation

³⁹ *Id.*

⁴⁰ *Id.*

⁴¹ *Id.*

⁴² *Id.*

⁴³ *Id.*

⁴⁴ *Id.*

⁴⁵ *Id.*

⁴⁶ *Id.*

⁴⁷ *Id.*

of so-called “designer babies”; and third is a child welfare argument that debates whether a savior sibling will be physically, emotionally, or physiologically harmed.

i. Children as Commodities

One of the most common objections to this procedure lies in the idea that it is wrong to bring children into existence “conditionally.”⁴⁸ This stems from Immanuel Kant’s famous dictum “Never use people as a means but always treat them as an end.”⁴⁹ For example, in medical environments, anyone who receives a blood transfusion has used the blood donor as a means to their own ends.⁵⁰

In the view of some, creating a savior sibling is merely conceiving a child to be used as an instrument and an object in curing another child.⁵¹ However, from a broader perspective, parents have children for all different sorts of instrumental reasons.⁵² For example, benefits to the couple’s marriage, continuity of the family name, economic and psychological benefits to the parents, and providing a playmate for an already existing child.⁵³ In an article written by B.M. Knoppers, she states that most parents have a broad range of reasons and expectations when they decide to have children, which, she explains, instrumentalizes them to a degree.⁵⁴ This leads some authors to write that as long as the tissue donation would be ethical if performed on an existing child, bringing a child into the world to serve as a tissue donor is ethical if the child is

⁴⁸ Whitney Fasbender, *The Savior Child: Having a Child to Save a Sibling, Is This Right?*, 3 J. OF UNDERGRADUATE NURSING WRITING 1 (2009).

⁴⁹ *Id.*

⁵⁰ *Id.*

⁵¹ B.M. Knoppers, *Preimplantation Genetic Diagnosis: An Overview of Socio-Ethical and Legal Considerations: Annual Review of Genomics and Human genetics*, 201-221, 212 (2006).

⁵² See Fasbender, *supra* note 48, at 21.

⁵³ *Id.*

⁵⁴ See Knoppers, *supra* note 51, at 202.

also valued for him or herself.⁵⁵ As long as the parents intend to rear and love the donor child, this practice is acceptable.⁵⁶ Supporters of this practice argue that since these parents are making the focused effort to try and save their child, it suggests that they are caring and loving parents and makes it unlikely that they would treat a new born as a child that was only used to save another child.⁵⁷

ii. Creating “Designer Babies”

The next argument regarding savior siblings is that permitting the deliberate creation of savior siblings would be to step onto a slippery slope towards allowing “designer babies”.⁵⁸ The idea is that this technique is a first step towards allowing parents to use embryo testing to choose specific characteristics of their baby such as eye or hair color.⁵⁹ This is a fairly simple argument that exists out of fear of overuse of technology.

In an article written by Allison Ford, she explains that although PGD may seem like a “miracle”, it may have real-world implications.⁶⁰ She questions what would stop a couple from discarding an embryo based on sex if it is legal to discard an embryo based on faulty genes.⁶¹ Approximately forty-two percent of fertility clinics that offer the process of PGD do it for the purpose of allowing couples to choose the sex of their child.⁶² These clinics market the idea of

⁵⁵ *Id.*

⁵⁶ S.M. Wolf, *Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines, and Limits*, J. OF LAW MED. AND ETHICS 327-339, 330 (2003).

⁵⁷ K. Devolder, *Preimplantation HLA typing: Having Children to Save Our Loved Ones*, 31 J. MED. ETHICS 582-586, 584 (2005).

⁵⁸ See Fasbender, *supra* note 48.

⁵⁹ *Id.*

⁶⁰ Allison Ford, *Designer Babies: Good Idea or Slippery Slope?*, 2013, available at <http://www.divinecaroline.com/life-etc/designer-babies-good-idea-or-slippery-slope>, (last visited May 8, 2013).

⁶¹ *Id.*

⁶² *Id.*

sex-selective PGD as a method of balancing a family by allowing families with either several sons or several daughters to have a child of the opposite sex.⁶³ However, some couples purely have a sex preference regardless of the sex of other children.⁶⁴

As will be discussed in detail in the law section below, the United States has no laws against couples choosing the sex of their children, while other countries have deemed the process illegal.⁶⁵ Ford enunciates the fact that if scientists are able to isolate genes that are responsible for eye color, hair color, or intelligence, then, arbitrarily, couples will be able to create their own “perfect child”.⁶⁶ There is also a fear that these types of techniques would eventually breed out certain characteristics that are deemed as generally unwanted.⁶⁷ In a study conducted by New York University, respondents expressed their willingness to screen their embryos for height, athletic prowess, and intelligence.⁶⁸

The last point Ford makes is that, although for most scientists the goals for PGD are to prevent disease as opposed to creating the perfect child, “our abilities have outpaced our understanding of what is ethical.”⁶⁹ She questions whether this type of technology would get to a point where it is no longer good enough to have a healthy child, but to have a “perfect child.”⁷⁰

iii. The Welfare of the Child

The “welfare of the child” argument is the argument that is heavily touched on in *My Sister’s Keeper*. The premise of the child welfare argument is that sibling saviors will have

⁶³ *Id.*

⁶⁴ *Id.*

⁶⁵ *Id.*

⁶⁶ *Id.*

⁶⁷ *Id.*

⁶⁸ *Id.*

⁶⁹ *Id.*

⁷⁰ *Id.*

inferior lives to those children who are not born to save another.⁷¹ Medically, it has been suggested that embryo biopsy for PGD does not seem to produce adverse physical effects in the short term, but it is too early to exclude the possibility of later effects.⁷² Other factors include whether the donations are successful, whether more are required, and whether the sick child is cured or dies.⁷³ Not only might the new baby know he or she is a savior sibling, but knowing that they were an unsuccessful savior sibling could be even worse.

Proponents of PGD concede that if the child finds out that he or she was wanted not for himself or herself, but rather for the ulterior purpose of assisting a sibling to live, this may cause psychological harm. However, it is also argued that it is just as likely that that child will feel pride and contentment in the knowledge that he or she is responsible for saving the life of a sibling. When it comes to psychological harm, there are two theories. First, that the future child may suffer harm if he or she finds out that they were not wanted for themselves, but as a means to save the life of a sibling.⁷⁴ Second, that a child conceived for this reason is likely to enjoy a less close and loving relationship with its parents who are less likely to value and nurture the child given they had the child primarily to save the life of a sibling.⁷⁵ Therefore, opponents of this practice suggest that no matter how the parents choose to love and care for the new baby, it still does not change the fact that this child will most likely be aware that they were born for the sole reason of saving their sibling.⁷⁶

When the donor child eventually can fully understand his or her role in these types of events, it is argued that the child may agree with the decision the parents have made and the

⁷¹ See Fasbender, *supra* note 48.

⁷² See Duke, *supra* note 22.

⁷³ See Knoppers, *supra* note 51.

⁷⁴ *Id.*

⁷⁵ *Id.*

⁷⁶ *Id.*

impact that this child has had on the life of his or her sibling.⁷⁷ However, if the child finds out that he or she was unable or is still unable to act as a tissue donor for the sibling, they are much more likely to be psychologically damaged.⁷⁸

The related philosophical argument that ties in here rests upon the presumption that the alternative for a savior sibling is not another life in which he or she was conceived in another way, but non-existence.⁷⁹ Therefore, the argument is based on the proposition that those who object to the creation of a savior sibling must therefore believe that a sibling would have been better off were it never to have existed.⁸⁰

The welfare of the child argument also incorporates the extent of which this new child can be expected to be a life long donor subject to repeated tests and procedures.⁸¹ Along with this are the risks associated with the procedures and the extent of which the body is invaded.⁸² According to an article written by K. Devolder, the ethical standard that should be employed in these types of situations is what would be acceptable if the donor child already existed.⁸³ The harvesting of umbilical cord blood is widely accepted already since it entails no physical intrusion and no harm to the embryo.⁸⁴ Bone marrow transplants from young children to their siblings have also become widely accepted.⁸⁵ However, harvesting vital organs from children is not acceptable in light of the risks involved for the donor child.⁸⁶

⁷⁷ *Id.*

⁷⁸ *Id.*

⁷⁹ *Id.*

⁸⁰ *Id.*

⁸¹ See Wolf, *supra* note 56.

⁸² *Id.*

⁸³ See Devolder, *supra* note 57.

⁸⁴ *Id.*

⁸⁵ *Id.*

⁸⁶ *Id.*

Bone marrow donation, for instance, involves a number of risks.⁸⁷ These risks include general anesthesia, infection, pain, discomfort, and the risks that are associated with blood transfusion.⁸⁸ Donating an organ involves even more physical risk than a bone marrow donation.⁸⁹ To request a savior sibling to donate their organs unfairly subjects themselves to physical pain and weakness that reaps no benefits for the savior child.⁹⁰

When it comes to the moral considerations, Knoppers separates them into two main points of view that are widely debated. The first view is that the embryo is a new human life entitled to full moral status from the time of fertilization because from that time it holds the potential to develop into a complete human being.⁹¹ The other view is that the embryo has some moral status from fertilization, but to a lesser extent than a born human being, and gradually acquires “full” moral status during development.⁹² This paper is focused on the ethical considerations rather than the moral aspects of savior siblings.

iv. Tests

There is a sub-argument regarding the welfare of a child called the net-benefit argument. In an article written by Sheldon and Wilkinson in 2001, they make it clear that they believe that an embryo should be exposed to the risks of PGD only if it (or the person it becomes) is likely to derive enough benefit to outweigh those risks.⁹³ Basically, the potential child is thought to be

⁸⁷ See Fasbender, *supra* note 48, at 21.

⁸⁸ *Id.*

⁸⁹ *Id.*

⁹⁰ Amy T. Y. Lai, *To Be or Not To Be My Sister's Keeper?*, 32 J. LEGAL MED. 261 (2011).

⁹¹ See Knoppers, *supra* note 51.

⁹² *Id.*

⁹³ See Fasbender, *supra* note 48.

like an existing patient. Since the embryo is viewed as a potential child, proponents of this reasoning afford the embryo the same moral status as that of a born child.⁹⁴

In an article written by S.M. Wolf, she explains that PGD to avoid serious and early-onset illness in a child-to-be is widely accepted.⁹⁵ This type of screening of an embryo reduces the chances of parents having a child that is affected by a genetic or chromosomal disorder in which the parents are possibly faced with the decision of aborting the child or living with the challenges of raising an ill or disable child.⁹⁶ When PGD is used in this manner, it is being done in the best interest of the embryo or the person that that embryo will become.⁹⁷ However, controversy arises when PGD is used solely for tissue typing because the only one who benefits from that type of screening is the existing sick child.⁹⁸

Tissue typing “is a group of procedures that determines the type of histocompatibility antigens on a person’s cells or tissues.”⁹⁹ The procedure of tissue typing is generally used prior to transplantations in order “to ensure as close a match as possible between the donor and the recipient.”¹⁰⁰ If the antigens are not perfectly matched, there is a change that the donated tissue will be rejected by the recipient.¹⁰¹

v. Ethical Conclusion

The idea of a savior sibling will forever be debatable. Among the three main arguments which include children as commodities, designer babies, and the welfare of the child, only one

⁹⁴ *Id.*

⁹⁵ S.M. Wolf, *Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines, and Limits*, J. OF LAW MED. AND ETHICS 327-339, (2003).

⁹⁶ *Id.*

⁹⁷ *See* Devolder, *supra* note 57.

⁹⁸ *Id.*

⁹⁹ Farlex, Inc., *Medical Dictionary*, 2013, available at <http://medical-dictionary.thefreedictionary.com/tissue+typing>, (last visited May 9, 2013).

¹⁰⁰ *Id.*

¹⁰¹ *Id.*

argument holds much merit. That argument is the welfare of the child. When it comes to children as commodities, there is more convincing literature that turns on the fact that life is better than non-existence. Basically every argument against savior siblings gets fumbled when it comes to the fact that life is better than non-existence.

Children as commodities fails as an argument not only because of the point discussed above, but because every day couples are having children for many other reasons besides “the right ones”. There is really no way to regulate or determine why a child is born into this world.

The argument that the allowance of savior siblings will lead down a slippery slope and eventually lead to designer babies is a weak argument as well. It is extremely difficult to categorize together having a child to save another child with having a child with blue eyes instead of brown. The two arguments should not be places within the same category as they are completely different in nature and scope.

However, the slippery slope argument is a strong argument in the United States where there is no regulation at all of the use of PGD. Any type of technology that is this advanced and this life-impacting should be regulated or it could get out of hand. In countries where regulations are clearly set in place, there are no worries of a slippery slope because it would be illegal to have a child born with exact specifications like hair color, eye color, and skin type. This argument makes it more imperative for the United States to step up and follow the examples of other countries before it is too late and our technology get abused. The laws of the U.S. and other countries to regulate PGD will be discussed thoroughly in the next section.

The argument with the most merit is the argument about the welfare of the child. There’s no possible way to know exactly what the outcome will be of the already existing child if a

savior sibling is created to save that child. However, what parent wouldn't give their child every ounce of a chance of survival?

IV. The Laws

While the ethical debate will be forever on-going, the demand for PGD for stem cell transplantation from similarly-situated families to the Nash's soared as news spread about their experience.¹⁰² Moreover, such demand is likely to continue to grow exponentially given the recent success and the variety of diseases for which it can be used.¹⁰³ Therefore, it is quite perplexing that the United States, being as far-reaching in medical, moral, and ethical implications, has allowed PGD to go forth largely unregulated.¹⁰⁴

Other countries, such as Australia and the United Kingdom, so closely oversee the use of both IVF and PGD and other countries such as Austria, Germany, Ireland, and Switzerland have outlawed PGD altogether.¹⁰⁵ There are four different ways that PGD can be regulated. In the next sections, this paper will analyze those ways and those countries that regulate IVF and PGD.

i. Statutory Ban on PGD

A statutory ban on PGD simply means that PGD is not allowed to be performed. Countries among this category include Germany, Switzerland, Ireland, Western Australia, and

¹⁰² See Lai, *supra* note 90.

¹⁰³ *Id.*

¹⁰⁴ *Id.*

¹⁰⁵ *Id.*

Austria.¹⁰⁶ These types of bans are put in place for a number of ethical, moral and social reasons.¹⁰⁷ For example, Germany currently does not allow PGD based on the premise that the embryo has the right to life and performing PGD is unacceptable because it will likely result in the destruction of embryos that carry disease-linked genes.¹⁰⁸

This type of ban has led to what is known as “medical tourism.”¹⁰⁹ This term implies that a couple who lives where there are restrictive laws on PGD will travel to different areas of the world to obtain treatment where it can be legally done.¹¹⁰ There are several problems with medical tourism.¹¹¹ First, patients tend to lack the proper follow-up care, and, therefore, complications of the surgery or the side effects of certain drugs are not taken care of.¹¹² Patients may also not tolerate travel well, or may be subject to catching diseases in the countries they travel to for medical care.¹¹³ In a survey carried out by the British Association of Plastic, Reconstructive and Aesthetic surgery, thirty-seven percent of 203 people had complications arising out of overseas surgery.¹¹⁴

ii. Statutory Mandatory Licensing

This type of regulation occurs when a section of the government regulated PGD by requiring a clinic to obtain a license before they can perform PGD.¹¹⁵ Countries that follow this

¹⁰⁶ *Id.*

¹⁰⁷ *Id.*

¹⁰⁸ Savior Siblings, *Is PGD Being Regulated?*, 2009, available at http://ourethicaljourney09.blogspot.com/2009_06_01_archive.html, (last visited May 2, 2013).

¹⁰⁹ *Id.*

¹¹⁰ *Id.*

¹¹¹ Lamk Al Lamki, *Medical Tourism, Beneficence or Maleficence?*, 11 SULTAN QABOOS UNIV. MED. J. 444-447, (2011).

¹¹² *Id.*

¹¹³ *Id.*

¹¹⁴ *Id.*

¹¹⁵ See Savior Siblings, *supra* Note 108.

structure include the UK and France.¹¹⁶ In the UK, PGD is regulated by the Human Fertilization and Embryology Act (HFEA).¹¹⁷ This Act was enacted in 1990.¹¹⁸ The UK allowed for PGD to be performed to test for severe genetic diseases and tissue type matching for savior siblings under strict criteria. However, the UK does not allow gender selection.¹¹⁹ Under the UK's regulations, a clinic must apply for a new license for every new genetic disease they would like for test for in an embryo. What this form of regulation does is create clear and legally enforceable rules.¹²⁰ However, is it fair to leave the decision of unacceptable vs. acceptable uses of PGD in the hands of others?¹²¹

The main focus of the HFEA is to monitor and license any clinics that perform IVF, donor insemination, or clinics that store gametes and embryos.¹²² The HFEA is also in charge of regulation embryo research, while also creating a Code of Practice with guidelines for the clinics performing these types of treatments.¹²³ The HFEA also provides advice to parents, patients, and physicians and keeps a register of all children born from these treatments.¹²⁴

iii. US position

No law or regulatory process has been enacted in the U.S. to limit the use of PGD to cure disease. The United States is currently a non-regulatory country.¹²⁵ Because of this, the uses of

¹¹⁶ *Id.*

¹¹⁷ Genetics and Public Policy Center: *Reproductive Genetic Testing*, 2000, available at http://www.dnapolicy.org/pub.reports.php?action=detail&report_id=6, (last visited May 2, 2013).

¹¹⁸ *See* Savior Siblings, *supra* note 80.

¹¹⁹ *Id.*

¹²⁰ *Id.*

¹²¹ *Id.*

¹²² HFEA, *Fact Sheet 2: About the HFEA*, available at http://www.hfea.gov.uk/docs/ToftFactSheet2_AboutHFEA.pdf, (last visited May 9, 2013).

¹²³ *Id.*

¹²⁴ *Id.*

¹²⁵ *See* Genetics and Public Policy Center, *supra* Note 117.

PGD are left to the discretion of its providers.¹²⁶ What this sort of regulation does is avoid governmental interference in personal choices and the continuation of innovative scientific progress without regulation.¹²⁷ However, there are many flaws in a system like this. Not having any type of regulation gives the authority to PGD clinics to make their own decision on moral and ethical issues concerning PGD.¹²⁸ Each clinic will make their own separate policies and services.¹²⁹ With non-regulation, one clinic can allow using PGD to select the gender of the baby, while others will use it for screening for severe genetic conditions.¹³⁰ Non-regulation gives too much power to the PGD clinics to make their own moral and ethical decisions.¹³¹ More than two-thirds of the approximately fifty fertility clinics worldwide offering PGD are found in the United States because of the lack of regulation.¹³²

iv. Self-Regulation by Professional Organizations

Under this type of self-regulation, PGD is regulated through guidelines issued by professional organizations.¹³³ If a clinic fails to abide by these guidelines, it can result in the withdrawal of a clinic's membership in the organization.¹³⁴

An example of a country that regulated PGD through professional organizations is Japan.¹³⁵ Japan has two professional organization designed for this purpose.¹³⁶ Japan's guidelines

¹²⁶ *Id.*

¹²⁷ *Id.*

¹²⁸ *Id.*

¹²⁹ *Id.*

¹³⁰ *Id.*

¹³¹ *Id.*

¹³² *Id.*

¹³³ *Id.*

¹³⁴ *Id.*

¹³⁵ *Id.*

¹³⁶ *Id.*

require that PGD only be apply to “serious hereditary disorders,” or, in the case of sex selection, to “serious sex-linked recessive hereditary disorders.”¹³⁷ PGD clinics must get approval from the organizations before they can perform PGD.¹³⁸

In the U.S., PGD service suppliers only need to follow the ethical guidelines of two committees: the American Society for Reproductive Medicine and the American Medical Association.¹³⁹ The American Society for Reproductive Medicine addresses the general use of the PGD, while the American Medical Association states that the use of PGD is permissible “to prevent, cure, or treat genetic disease” and not for the “selection on the basis of non-disease related characteristics or traits.”¹⁴⁰ This is considered self-regulation, rather than regulation on a state or federal level.

Also in the U.S. every use of Assistive Reproductive Technology (ART) must be reported.¹⁴¹ In 1992, the Fertility Clinic Success Rate and Certificate Act was passed by Congress which required each ART program to complete an annual report.¹⁴² This annual report must include the success and failure rates of ART at each clinic.¹⁴³

V. Cases in the US

Since the U.S. is in the non-regulated category, there have not been cases that deal directly with the use of PGD for use to cure a disease, but there have been several cases that have utilized the ideals discussed above. Two of those cases are Strunk v. Strunk and Hart v. Brown.

¹³⁷ *Id.*

¹³⁸ *Id.*

¹³⁹ *Id.*

¹⁴⁰ *Id.*

¹⁴¹ Society for Assisted Reproductive Technology, *Who is to Report ART Cycles?*, 1996, available at <http://www.sart.org/detail.aspx?id=1911>, (last visited May 9, 2013).

¹⁴² *Id.*

¹⁴³ *Id.*

It is important to discuss these cases in regards to the U.S. because, since the U.S. is non-regulated, it is the only type of reference available in regards to this type of procedure.

In *Strunk v. Strunk* (1969), Arthur Strunk and Ava Strunk were the parents of two sons.¹⁴⁴ One of those sons was Tommy Strunk who at the time was twenty-eight years old, married, an employee of the Penn State Railroad, and a part-time student at the University of Cincinnati.¹⁴⁵ Tommy was suffering from chronic glomerulus nephritis, a fatal kidney disease, and was being kept alive by frequent treatment on an artificial kidney.¹⁴⁶ However, that procedure could not be continued much longer.¹⁴⁷ Jerry Strunk was twenty-seven years old at the time this was occurring.¹⁴⁸ He was deemed incompetent, and had been committed to the Frankfort State Hospital and School, an institution maintained for the feeble-minded.¹⁴⁹ His I.Q. was approximately 35, which puts him in the mental age category of a healthy six year old.¹⁵⁰

It was determined that Tommy, in order to survive, would have to have a kidney transplant.¹⁵¹ The entire family was tested and found to be incompatible except Jerry.¹⁵² Ava Strunk petitioned the county court for authority to proceed with the operation.¹⁵³ The court found that the operation was necessary, that under the peculiar circumstances of the case it would not only be beneficial to Tommy, but also beneficial to Jerry because Jerry was greatly dependant upon Tommy, both emotionally and psychologically.¹⁵⁴ The court continued to explain that

¹⁴⁴ *Strunk v. Strunk*, 445 S.W.2d 145 (1969).

¹⁴⁵ *Id.* at 145.

¹⁴⁶ *Id.*

¹⁴⁷ *Id.*

¹⁴⁸ *Id.* at 146.

¹⁴⁹ *Id.*

¹⁵⁰ *Id.*

¹⁵¹ *Id.*

¹⁵² *Id.*

¹⁵³ *Id.*

¹⁵⁴ *Id.* at 149.

Jerry's well-being would be jeopardized more severely by the loss of his brother than by the removal of his kidney.¹⁵⁵ This case is an example of the net-benefit test.

In *Hart v. Brown* (1972), Peter Hart and Eleanor Hart were the parents and natural guardians of Kathleen and Margaret Hart, identical seven year old twins.¹⁵⁶ Kathleen Hart was a patient in the Yale-New Haven Hospital suffering from hemolytic uremic syndrome and awaiting a kidney transplant.¹⁵⁷ This disease is a disorder of the kidneys which clogs within the small blood vessels.¹⁵⁸ The physicians in this case were the defendants and had in the past performed successful kidney transplants and were of the opinion that a successful transplantation operating could be performed on the minors, Kathleen as the donee and Margaret as the donor.¹⁵⁹

The parents of the children have given their permission for the operation of the kidney, but the physicians were unwilling to perform the operation and the hospital refused to use their facilities unless the court declared that the parents had the right to give their consent to the operation upon the minor twins.¹⁶⁰ The operating surgeon testified that the surgical risk is no more than the risk of the anesthesia, the procedure would last about two and one-half hours, and that there would be some minor postoperative pain but no more than in any other surgical procedure.¹⁶¹ Assuming an uneventful recovery, the child would be able to engage in all of the normal life activities of an active young girl.¹⁶² The only real risk would be the trauma to the one remaining kidney in the donor.¹⁶³ The legal problems discussed in this case were the balancing of

¹⁵⁵ *Id.*

¹⁵⁶ *Hart v. Brown*, 29 Conn. Supp. 368, (1972).

¹⁵⁷ *Id.* at 369.

¹⁵⁸ *Id.*

¹⁵⁹ *Id.*

¹⁶⁰ *Id.* at 370.

¹⁶¹ *Id.*

¹⁶² *Id.*

¹⁶³ *Id.*

the rights of the natural parents and the rights of minor children, more focused, the rights of the donor child.¹⁶⁴

The court stated that it appeared that the natural parents would be able to substitute their consent for that of their minor children after a close, independent and objective investigation of their motivation and reasoning.¹⁶⁵ This had been accomplished in this matter by the participating of a clergyman, the defendant physicians, an attorney guardian ad litem for the donor, the guardian ad litem for the donee, and indeed, through the court itself.¹⁶⁶

The court cited to *Strunk v. Strunk* pointing out that the difference between the two cases was subtle.¹⁶⁷ The donor in the instant case was almost eight years old. In the *Strunk* case, the donor was an adult with the mental capacity of a six year old.¹⁶⁸ The risks to the donee in the *Strunk* case were more than what was presented in the present case.¹⁶⁹ The court concluded that natural parents of a minor should have the right to give their consent for the kidney transplant.¹⁷⁰

These cases, and cases like them, show the court's attitude behind the idea of a savior sibling in the United States.

VI. Opinions and Suggestions

a. The Best and Worst Regulatory Choices

The United States' example of non-regulation is not one which should be followed. As stated above, this type of regulatory process leaves the process of implementing PGD to the discretion of its providers. Because of this, clinics will make their own separate policies and

¹⁶⁴ *Id.*

¹⁶⁵ *Id.*

¹⁶⁶ *Id.*

¹⁶⁷ *Id.* at 371.

¹⁶⁸ *Id.*

¹⁶⁹ *Id.*

¹⁷⁰ *Id.*

services which negates the idea of having a uniform system of the law. Non-regulation gives too much power to the PGD clinics to make life-impacting moral and ethical decisions. If PGD is not regulated, it will be taken advantage of and eventually led down the slippery slope path that is imperative to avoid.

The idea of using a non-parental guardian, as in the cases discussed above, and advocating on a child's behalf, stems from having a non-regulatory system set in place. Cases like *Hart v. Brown* arise because the physicians choose to not perform operations without court's approval. This is obviously not always the case and since PGD is not regulated, many cases go unheard.

The idea of a statutory ban on PGD is on the other side of the spectrum. As mentioned above, these countries disallow any form of the use of PGD whether it is to choose the sex of a child or to save another child's life. The issue with this type of ban is fairly obvious. If one country bans the use of PGD and a child is sick, the family will temporarily take a "medical tour" to a country where it is legal and get the medical help they need. It is not right to impose a single moral or ethical perspective on others when there are so many different views and so many different type of cases and levels of importance.

Statutory mandatory licensing is a step in the right direction, especially when it comes to the UK. The UK's use of the Human Fertilization and Embryology Act should be an example for all countries to learn from. Each individual clinic is under the same set of guidelines and rules and must apply for a license for each new disease that they would like to test an embryo for. This helps the HFEA keep track of developments and set clear rules.

Regulation by professional organizations is by far the best choice of all four choices. This is basically what is known as a "case-by-case" basis, which is exactly how PGD should be

handled. The UK, for example, although structured so tightly, does not allow for the use of PGD for sex selection. At first glance, this might seem like the right guideline to have so that couples are not abusing the power of being able to choose the sex of their child. However, some serious sex-linked hereditary disorders have a chances of occurring as high as eighty percent in males, but only ten percent in females. In these types of cases, the technology we have in the world today should be used to potentially avoid bringing a child into the world that has only a twenty percent chance at being healthy.

VII. Conclusion

The use of IVF and PGD should be regulated on a case-by-case basis in order to give each child and each situation its rightful time to be heard and evaluated. If our modern technology can be used to save lives, there is no reason for that type of knowledge to be unavailable. However, a lack of regulation can lead to obvious misuse of this type of technology, and, therefore regulation is imperative.